

Understanding Hospice, Palliative Care and End-of-life Issues

**Huntington's Disease Society of America
June 2009**

**Roseanne Berry, MS, RN
RBC Consulting, LLC
roseanne@rbcconsultingllc.com**



Huntington's Disease Society of America

The information provided by speakers in workshops, forums, sharing/networking sessions and any other educational presentation made as part of the 2009 HDSA convention program is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Presenter Disclosures

Roseanne Berry

No relationships to disclose
or list



Huntington's Disease Society of America

Purpose

- Learn about palliative care and hospice and how they can help improve comfort and quality of life
- Discover the value of communicating end-of-life wishes
- Discuss advance directives and end-of-life care decisions
- Identify resources that can help you complete your advance directives

Palliative Care

Palliative Care

- Treatment that enhances comfort and improves the quality of an individual's life.
- The goal is to relieve the pain, symptoms and stress of serious illness – whatever the prognosis.
- It is appropriate for people of any age and at any point in an illness.

Curative Care versus Palliative Care

- Curative care

- Focuses on quantity of life and prolonging of life

- Palliative care

- Focuses on quality of life and death, and views death as a natural part of life

Palliative Care

- Early introduction of palliative care is imperative.
- Palliative care team works to improve care and quality of life, emphasizing:
 - continuity of care,
 - communication,
 - symptom management,
 - crisis prevention and early crisis management

Palliative Care

- Team assists patients and families in articulating wishes and goals of care, developing a plan to achieve goals.
- No longer able to live independently, care turns toward adaptation to advanced illness and disability and issues of life closure.

Palliative Care

- Palliative care teams
 - Hospital based
 - Hospice based
- How Long Can Care Be Provided?
 - Depends on care needs
- Who Pays?
 - Some treatments and medications may be covered by Medicare, Medicaid and private insurance
 - Palliative care is not a “package deal”

How to Get Palliative Care

- **Step 1) Talk to your doctor**
- **Step 2) Find a Palliative Care Team**
 - Hospital based palliative care
www.getpalliativecare.org
 - Home care based palliative care National Hospice and Palliative Care Organization
www.nhpco.org
- **Step 3) Meet with the Palliative Care Team**



Hospice

Hospice

- Provides support and care for those in the last phases of life-limiting illness.
- Recognizes dying as part of the normal process of living.
- Affirms life and neither hastens nor postpones death.
- Focuses on quality of life for individuals and their family caregivers.

Hospice Admission Criteria

■ General

- Life-limiting illness, prognosis is 6 months or less if disease takes normal course
- Patient wants hospice (consents to accept services)

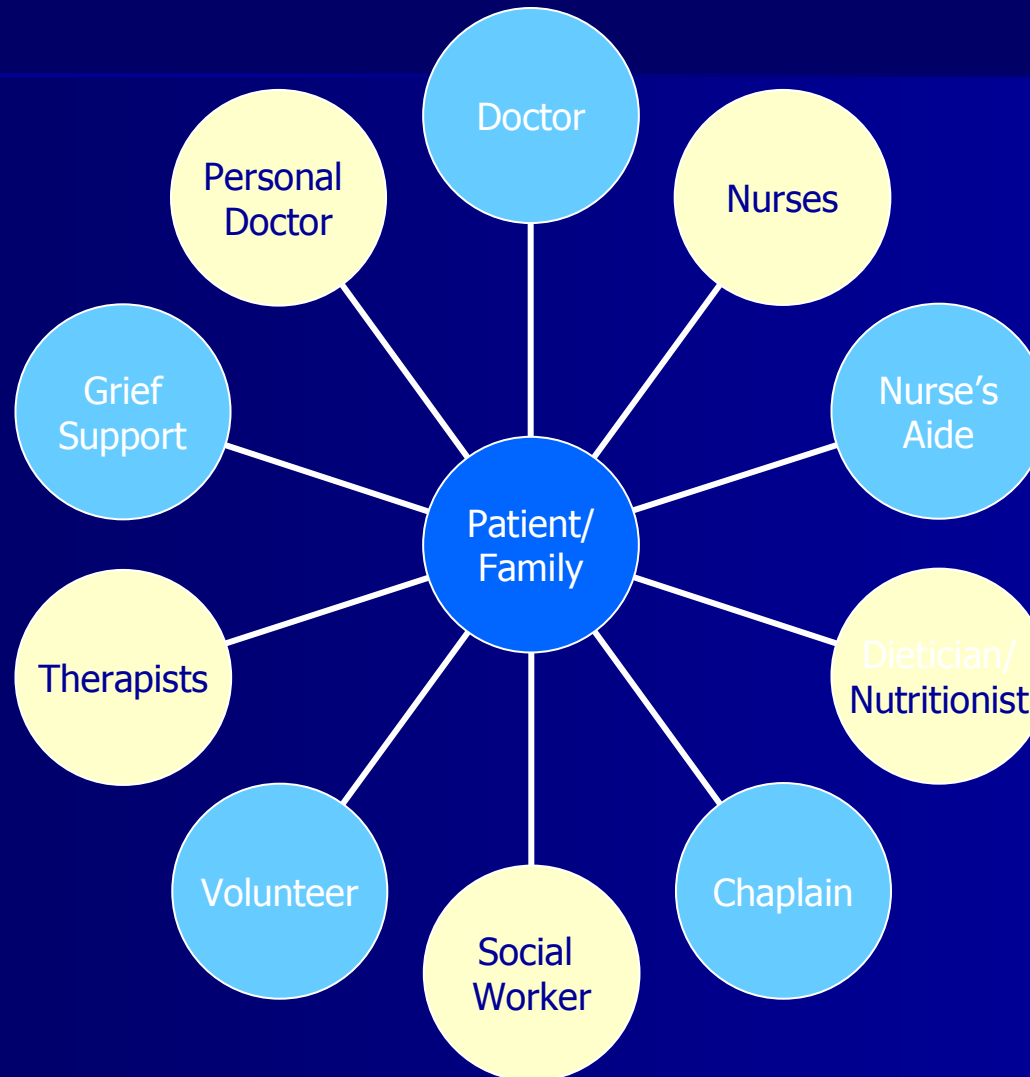
Core Aspects of Hospice

- Patient/family focused
- Interdisciplinary team
- Provides a range of services:
 - Interdisciplinary case management
 - Medications
 - Medical equipment
 - Medical supplies
 - Volunteers
 - Grief support

Additional Services

- Hospices offer additional services, including:
 - Inpatient hospice care
 - Inpatient respite care
 - Continuous home care
 - Residential care facility (optional)
 - Complementary therapies (optional)
 - Specialized pediatric team (optional)

Hospice Circle of Care



What about my doctor?

- You keep your own doctor.
- The hospice doctor has special training and experience and can assist your doctor if needed.
- Your hospice nurse will keep your doctor updated by phone.

Who Pays for Hospice?

- Medicare pays all costs related to hospice
- Medicaid pays all costs related to hospice
- Insurance-most have a hospice benefit
- Private pay

How to Get Hospice Care

- **Step 1) Talk to your doctor**
- **Step 2) Find a hospice**
 - National Hospice and Palliative Care Organization www.nhpco.org
- **Step 3) Interview the hospice**

Talking About End of Life Wishes

Why is talking so *important?*

- Conversations before the 'crisis' allow time for honest discussion, reflection and planning
- Opportunity to discover important information about yourself and your loved ones
- Most important gift you can give to prepare for end of life

Why is talking so *hard*?

- How do you feel about choices and care around the end of life?
- What do you want?
- What are you worried about?
- Who will make your decisions for you when you are unable?

Conversation Triggers

- Family gatherings
- Death of friend or colleague
- Newspaper & magazine articles
- Movies & books
- Sermons
- TV talk shows
- Financial planning
- Medical checkups

How To Communicate

- Step 1: Introduce the conversation
- Step 2: Explore personal beliefs and values
- Step 3: Define end-of-life wishes
- Step 4: Document wishes

Step 1: Introduce the Conversation

- Timing is everything!
- Private, comfortable place
- Begin with a conversation trigger
- Importance of expressing end-of-life wishes

Step 2: Explore Personal Beliefs and Values

- Engage in a conversation about beliefs and values
 - *Happiness*
 - *Challenging Times*
 - *Spirituality*
 - *Family/Growing Up*
 - *Personal Values*
 - *Lifetime Legacies*

Step 3: Define End-of-Life Wishes

Choices

- Would you want to withhold or withdraw medical treatment if that treatment will only prolong dying?
- Do you want CPR (to be resuscitated) if you stop breathing or your heart stops?
- Would you want to use mechanical ventilation (machines that keep you breathing)?
- Would you want tube or IV feedings?

Step 4: Document Wishes

- Complete your Advance Directives
 - Living Will
 - Medical Power of Attorney
- Inform others
 - Health care professionals, physician
 - Family members, friends, self

Advance Directives

What are *Advance Directives*?

- A written statement of your wishes, preferences and choices regarding end-of-life health care decisions
- A tool to help you think through and communicate your choices
- Only used:
 - if you are seriously ill or injured AND
 - Unable to speak for yourself

What Are *Advance Directives*?

- State specific
 - Living Will
 - Medical Power of Attorney (MPOA)
 - Do Not Resuscitate (DNR) orders
 - Out of Hospital DNR
- Not transferrable state to state
 - Need to execute by state

What is a *Living Will*?

- A legal document with your wishes about medical treatment.
- You choose:
 - What you do want
 - What you don't want

What is a *Medical Power of Attorney?*

- A legal form that states who you want to make decisions about medical care
- Person is authorized to speak for you ONLY if you are unable to make your own medical decisions
- May also be called:
 - "health care proxy or agent"
 - "health care surrogate"
 - "durable power of attorney for health care" (DPOA)

Medical Power of Attorney

- Has power to make decisions
 - Receive/review medical information
 - Discuss with the medical team
 - Consent to or refuse procedures
 - Authorize transfers
- If you are the MPOA, make sure you understand what they want

Advance Directives: *Advantages*

- You are in charge of making your own decisions
- Documents can be changed anytime
- You DO NOT need an attorney
- Documents can help you express your wishes

Advance Directives: *Disadvantages*

- Advance Directives may not be available when needed
 - Don't transfer across states
- Living wills
 - May not be specific enough
 - May be overridden by a treating doctor
 - Does not immediately translate into doctor's order

Executing *Advance Directives*

- Do not need a lawyer to complete advance directive.
- Decide what type of life sustaining treatments you do not want.
- Discuss/inform with family and primary doctor.
- If you change your wishes, complete a new advance directive.

Executing *Advance Directives*

- Provide completed copies to your primary doctor, family members and medical power of attorney
- Carry wallet copy with you
- If your state recognizes out of hospital DNR, make sure to display and carry per your state's recommendations
- Have copy placed in your hospital and nursing facility medical record

Interesting to note...

- Most Americans – 88 percent – feel comfortable discussing issues relating to death and dying*
- Yet only 42% have a living will*

**National Survey on Death, Dying, and Hospice Care in America, VITAS Innovative Healthcare, 2004*

Resources



text size: [-](#) [A](#) [+](#)
[About Us](#) [Contact Us](#) [Support Us](#) [Resources](#) [Site Map](#)

[Home](#) [Planning Ahead](#) [Caring for Someone](#) [Living with an Illness](#) [Grieving a Loss](#) [Community](#) [Business](#)

Planning Ahead

Two years ago Sam told his adult children what kind of care he wanted if he could no longer make decisions. When Sam had a severe stroke his kids knew what to do.

Have you made a plan?

It's about how you LIVE.



Search [➤](#)

Download a state-specific living will or healthcare power of attorney

[Advance Directive](#)

Free resources on a wide range of end-of-life topics.

[Download Now!](#)

Are You Planning Ahead?

[Learn More ➤](#)

Are You Caring for Someone?

[Learn More ➤](#)

Are You Living with an Illness?

[Learn More ➤](#)

Are You Grieving a Loss?

[Learn More ➤](#)

Are You Reaching Your Community?

[Learn More ➤](#)

Are You a Caring Business?

[Learn More ➤](#)

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.



Lotsa Helping Hands

When Friends & Family Need Help

[Learn More](#)

National Hospice and Palliative Care
Organization



FREE Resources Available from *Caring Connections*

- Information about Hospice and Palliative Care
- State-specific advance directives
 - Introduction to Your State's Advance Directive
 - Instructions for Completing Your State's Advance Directive for Healthcare
 - Instructions for Completing Your State's Healthcare Power of Attorney
 - Legal form for Healthcare Power Of Attorney
 - Legal Form for Living Will
 - You Have Filled Out Your Advance Directive, Now What?

FREE Resources Available from *Caring Connections*

- Brochures available to download (many in Spanish):
 - Advance Care Planning Legal Issues
 - Advance Directives
 - Planning Ahead
 - Caregiving
 - End-of-Life Care
 - Grief
 - Pain
 - Pediatric
 - Planning for Long Term Care
 - Serious Illness
 - Spirituality

Resources

- National Hospice and Palliative Care Organization www.nhpco.org
 - Home care based palliative care
 - Hospice
- Hospital Based Palliative Care www.getpalliativecare.org

Questions?